



Focus on Progress

North Dakota's Children's Special Health Services (CSHS)

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Snapshot of North Dakota's Services

North Dakota's Children's Special Health Services (CSHS) provides the following services for children and youth ages birth to 21 with special health care needs (CYSHCN) and their families. The unit also promotes family-centered, community-based, coordinated services and systems of health care.

- The **Specialty Care Program** provides payment to providers serving eligible CYSHCN in order to increase access to pediatric specialty care.
- The **Multidisciplinary Clinic Program** provides comprehensive evaluations and coordination for CYSHCN to help families manage their child's chronic health condition.
- The **Care Coordination Program** provides community-based case management services for CYSHCN and their families.
- The **Metabolic Food Program** provides medical food and low-protein modified food products to individuals with PKU and MSUD in order to increase access to dietary treatment.
- The **Information Resource Center** provides public information services to families and providers in order to increase access to health care information and resources.
- **Data System Development** within CSHS provides data on the health status of CYSHCN in order to support evidence-based decisions for program development and service delivery.
- **CSHS** provides leadership and support to state and local partners to implement health service system improvements.



Progress in Building a System of Care

In North Dakota, 12.4% or 19,651 children ages 0-17 have special health needs (National Survey of CYSHCN, 2001). All states are striving to achieve a community-based system of services for all families of children and youth with special health care needs by the year 2010. The table below reflects North Dakota's progress in achieving a system of care for CYSHCN and compares it to the nation at large.

Snapshot of North Dakota's Children & Youth with Special Health Needs*

Child Health

17% experienced health conditions that frequently affected their daily activities (23% US).

Impact on Family

24% of families experienced financial problems due to their child's health needs (21% US).
15% of families spent more than 11 hours a week providing or coordinating health care for their child (14% US).

Family-Centered Care

30% of families did not consistently receive care that was family-centered (33% US).

Access to Care

13% had one or more unmet needs for specific services (18% US).
19% had problems getting a referral for specialty care (22% US).
12% did not have a usual source of medical care or relied on emergency rooms (9% US).

Insurance

31% did not have adequate insurance coverage (34% US).
13% did not have insurance at some point in the past year (12% US).

*Child and Adolescent Health Measurement Initiative (2005). *National Survey of Children with Special Health Care Needs 2001*, Data Resource Center on Child and Adolescent Health Web site. Retrieved 8/19/05 from www.cshcndata.org.

State Accomplishments

All 50 states and territories are in the process of achieving six national outcomes for CYSHCN, as part of the *President's New Freedom Initiative* by 2010. North Dakota's efforts to achieve each outcome are listed below:

Outcome #1 Families as Decision-Makers and Satisfied: CSHS supports a 9-member Family Advisory Council that meets quarterly to review program and policy decisions. Unit staff conduct an annual telephone survey to monitor family satisfaction. CSHS has strong partnerships with Family Voices and the Family-to-Family Support Network, two family organizations that provide health information and emotional support services within ND. Training that promotes family-professional collaboration is available through an annual Family Connections Conference.

Outcome #2 Medical Home: CSHS continues to promote the use of a medical home for CYSHCN through the distribution of medical home information. In the past, CSHS provided leadership in medical home assessment and planning supported in part through an American Academy of Pediatrics CATCH grant. More recently, a medical home leadership training was attended by a team of individuals looking to establish medical homes in ND. The MN Medical Home project has mentored ND's team as they began initiating the steps needed to pilot practice-level medical homes in ND. CSHS also provides state and county level care coordination for eligible CYSHCN.

Outcome #3 Adequate Insurance: CSHS provides diagnostic and treatment services through its Specialty Care Program to fill gaps in services not covered by the child's primary source of health care coverage. CSHS staff coordinated with other state-level program staff to write and submit a Medicaid waiver for children with extraordinary medical needs. Unit Staff attend Medicaid policy meetings to provide input regarding CYSHCN.

Outcome #4 Screening: The Newborn Screening and Follow-up program, a shared effort within the Department of Health and Department of Human Services, provides expanded metabolic screening for infants born in ND along with metabolic formula and food for individuals with PKU and MSUD. The ND Early Hearing Detection and Intervention program is a collaborative project between CSHS and the ND Center for Persons with Disabilities at Minot State University. ND EHDI is helping community partners assist children and their families that require further hearing screening or evaluation after hospital discharge. CSHS serves as the lead agency for the ND Birth Defects Monitoring System, a passive surveillance program to track birth defects.

Outcome #5 Integrated Community-Based Services: In collaboration with community partners, CSHS manages and funds multidisciplinary clinic services for CYSHCN and their families. These clinics are a valued service for families and have the added benefit as a source of pre-service training for healthcare providers. Annual training for county social service staff and public health nurses enhances local capacity building. CSHS also participates in interagency workgroups and committees to improve access to services for CYSHCN.

Outcome #6 Transition to Adult Life: CSHS staff is active on ND's Transition Steering Council. Some of the council's activities include state transition planning and education through a State Transition Conference that focuses on youth transition from school to work, pediatric to adult health care and home to independent living. Each year CSHS provides an annual outreach mailing to promote health care transition for youth 14-20 years of age.

Useful North Dakota Web Sites & Links

- **CSHS Homepage:** <http://www.nd.gov/humanservices/services/medicalserv/cshs/>
- **Family Voices of ND:** <http://www.fvnd.org>
- **Early Intervention:** <http://www.nd.gov/humanservices/services/disabilities/earlyintervention/parent-info/index.html>
- **Family to Family Support Network:** <http://www.med.und.nodak.edu/depts/rural/family/>
- **ND Early Hearing Detection & Intervention:** <http://ndcpd.misu.nodak.edu/1stsounds/>
- **ND Dept. of Health:** <http://www.health.state.nd.us/>
- **ND Dept. of Public Instruction - Transition:** <http://dpi.state.nd.us/transitn/>
- **State Data Profile:** <http://cshcndata.org/Content/StatePrevalence.aspx?geo=North%20Dakota>

A Community Snapshot



Cole is a 12-year old boy with a rare medical condition that led to complete blindness. He also had a kidney tumor that was treated with chemotherapy. Cole is served through the CSHS Specialty Care Diagnostic and Treatment program, which assists with the payment of his care after the family's insurance. Cole lives with his parents and younger brother, Clay, who has a cardiac condition and asthma. Clay is also served through the Specialty Care Diagnostic and Treatment program and the Multidisciplinary Clinic.

Cole enjoys Tae Kwon Do along with hunting, fishing and skiing with the Sporting Chance program. Clay, an active 9-year old, is involved with basketball, football and wrestling.

Their parents, Mike and Laura, appreciate the CSHS program. The Multidisciplinary Clinic program and the Specialty Care Diagnostic and Treatment program have assisted the family in coordinating and providing the care their sons need. Laura stated, "The medication assistance has been the biggest asset." County social service staff have helped link the family to other resources. To ease the process, county staff travel to the family's home to complete the eligibility and care coordination forms.

Mike and Laura feel strongly about helping other families that have children with special health care needs. They have been trained as veteran parents for the Family-to-Family Network. Laura also participates on the CSHS Family Advisory Council.